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Caracterização da qualidade de vida de pessoas com hanseníase em tratamento ambulatorial

Characteristics of people of quality of life with leprosy in outpatient treatment

Características de la gente de la calidad de vida con la lepra en tratamiento ambulatorio

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ABSTRACT

Objective: To characterize the quality of life of people with leprosy in outpatient treatment. **Method:** Exploratory-descriptive quantitative study with 59 subjects. To obtain the socioeconomic and clinical data of individuals used the questionnaire, and for the quality of life, the Short Medical Outcomes Study 36 - Item Short-Form Health Survey SF-36. Data analysis was adopted IBM SPSS statistical software. **Results:** 78% multibacillary; males 54.3%; mean age 45.9 years; economically active 67%. The SF-36 shows average scores calculated values up to score 50, but the physical and emotional aspects (score <50) Age was correlated to the areas of functional capacity and physical aspects, while sex was associated with mental health. **Conclusion:** The investigated population has adequate quality of life, though, it is observed that this is affected by the disease.

Descriptors: Leprosy, Quality of live, Nursing

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RESUMO

Objetivo: Caracterizar a qualidade de vida de pessoas com hanseníase em tratamento ambulatorial. **Método:** Estudo quantitativo exploratório-descritivo com 59 sujeitos. Para obtenção dos dados socioeconômicos e clínicos dos indivíduos utilizou-se formulário próprio e para a qualidade de vida, o questionário Short Medical Outcomes Study 36 – Item Short-Form Health Survey, o SF-36. Para análise dos dados adotou-se o software estatístico IBM SPSS. **Resultados:** 78% multibacilares; sexo masculino 54,3%; idade média de 45,9 anos; economicamente ativos 67%. O SF-36 aponta escores médios calculados em valores acima ao escore 50, exceto os aspectos físicos e emocionais (escore < 50) A idade esteve correlacionada aos domínios de capacidade funcional e aspectos físicos, enquanto o sexo esteve associado à saúde mental. **Conclusão:** A população investigada apresenta qualidade de vida adequada, embora, observa-se que esta se encontra afetada pela doença.

Descritores: Hanseníase, Qualidade de vida, Enfermagem.

RESUMEN

Objetivo: Caracterizar la calidad de vida de las personas con lepra en tratamiento ambulatorio. **Método:** Estudio cuantitativo exploratorio-descriptivo con 59 temas. Para obtener los datos socioeconómicos y clínicos de los individuos utilizaron el cuestionario, y para la calidad de vida, el Short Medical Outcomes Study 36 - Artículo Short-Form Health Survey SF-36. Se aprobó el análisis de datos de IBM SPSS software estadístico. **Resultados:** 78% multibacilar; varones 54.3%; edad media de 45,9 años; económicamente activa de 67%. El SF-36 muestra las puntuaciones medias calculadas valores de hasta anotar 50, pero los aspectos físicos y emocionales (puntuación <50) La edad se correlacionó con las áreas de la capacidad funcional y los aspectos físicos, mientras que el sexo se asocia con la salud mental. **Conclusión:** La población investigada ha adecuada calidad de vida, sin embargo, se observa que esta se ve afectada por la enfermedad.

Descriptores: Lepra, Calidad de vida, Enfermería

INTRODUCTION

Leprosy is a chronic infectious disease infectious, which committed mainly skin and peripheral nerves (ulnar, median, radial common Peroneal, posterior tibial, facial and trigêmio), and may leave serious sequelae when there is early intervention, demanding, therefore a multidisciplinary long-term follow-up, with a view to minimizing and/or absence of the emergence of deformities and consequent inability.¹

Considered a public health problem by the World Health Organization (who), especially when it comes to countries whose disease prevalence rates exceed 1 case every 10.000 inhabitants as in Brazil,² WHO has invested to decrease its incidence through educational, preventive measures and treatment, but Brazil still has an average of 47.000 new cases of leprosy per year in particular in the North, Northeast and Midwest, being ranked as the second country with the highest number of cases, accompanied by India in the first place.³

According to data from the Information System of the SUS, in the year 2012 38.210 new cases were confirmed

in Brazil leprosy, notified in the information system and reportable diseases-Sinan Net. When it comes to Paraíba 771 new cases of leprosy there was diagnosed, being 105 of these in the city of João Pessoa.⁴ Currently numbers of disease have reduced worldwide, close to 90%, when compared with 20 years ago, observing a decrease of 37,8% in the incidence of leprosy in Brazil.⁵

Clinically can manifest in four different ways (Indeterminate, Tuberculoid, Borderline and Vichorviana) that, except for the Indeterminate, are responsible for triggering the sick individual, serious injuries of peripheral nerves which may compromise nerve trunks and sensory branches. Such compromises bring as a consequence sensory disturbances and/or engine plus minor deformations, and skin ulcers, one of the most relevant.⁶

As a result of complications of neuropathy in patients hansenícos, the ulcerations are important gateway to infections that can worsen and lead patients to high complexity problems or even limb amputation compromised, causing them to serious and relevant disability, often interfering in socioeconomic life resulting in discrimination and stigmatization.⁷

Skin lesions and neuromotor commitment, leading the main physical disability in leprosy, worsening even more the self-esteem of patients, which leads to a significant drop in the quality of life and interferes directly in the social relations.⁸

In view of the current situation of leprosy in Brazil, the various factors that influence negatively on patients' quality of life and the impact that leprosy causes in the lives of individuals with this disease, this study aims to characterize the quality of life of patients with Hansen's disease, in a public hospital complex of reference for pathology located in the city of João Pessoa-PB.

METHOD

This is an exploratory and descriptive study, with a quantitative approach, developed at public hospitals in reference to the bearer of leprosy, located in the city of João Pessoa-PB. The Ethics Committee of the Health Sciences Center of Federal University of Paraíba under Protocol nº 465.129, CAAE 17868413.9.0000.5188, approved the research.

The convenience sample included leprosy patients who sought care in the outpatient dermatological nursing sector, between the months of February to April 2014. Were considered eligible individuals with confirmed diagnosis of Hansen's disease, independent of the clinical form, more than 60 days, who attended the service in the period of data collection; and agreed to participate in the survey, signing an informed consent.

Exclusion criteria were established: the new cases, those who have confirmed their diagnosis for just a month, taking into consideration that they may submit any of the stages of grief and non-acceptance of your condition; In addition

to the customers that do not have physical and mental conditions of the data collection form.

To obtain the economic and clinical characterization of individuals was built a proper form, and for the evaluation of quality of life, we used the questionnaire Short Medical Outcomes Study 36-Item Short-Form Health Survey, SF-36, which consists of 11 questions, composing so 36 items and covering 8 domains, as quoted below:^{9, 10}

1. Functional capacity: evaluates the presence and extent of limitations imposed on physical capacity;
2. Physical aspects: address the limitations in the type and amount of work, as well as how these limitations interfere in the activities of daily life of the people;
3. Emotional aspects: measure the impact of psychological aspects in the welfare of the person;
4. Pain: it has purpose to quantify the interference in the activities of daily life of patients;
5. General health: evaluates how the patient feels about their overall health;
6. Vitality: consider the level of energy and fatigue of patients;
7. Social aspects: analyze the integration of the individual in social activities;

Mental health: investigates the emotional outburst and psychological welfare.

Validation (translation and adaptation) of SF-36 was performed by Ciconelli in 1997. The evaluation of reproducibility was significant to the eight components of the SF-36 and the constructive validity has also been considered as satisfactory and statistically significant with regard to functional capacity, physical components, pain and general health were correlated to clinical parameters.¹⁰

As a cutoff point for each domain was the score 50, i.e., medium above 50 are considered satisfactory and unsatisfactory below this value.¹¹

For data analysis, we used the focus of quantitative method through, the descriptive and inferential statistics. Descriptive statistics was used to determine the measures of central tendency and variation, such as average, median and standard deviation. The inferential statistics was applied to carry out comparisons of levels of quality of life in relation to variables: sex, age, economic activity, the presence of ulcers and operational Classification. Were applied the Mann Whitney Test tests, student's t-test and Pearson correlation coefficient. Was previously fixed the significance level of 95% for associations. All the statistical processing was supported by IBM SPSS statistical software (formerly known as Statistical Package for the Social Sciences-SPSS) version 18.0.

RESULTS

The research consisted of 59 patients affected by leprosy, of which 32 (54,3%) are male and 27 (45,7%) female. The

middle ages presented was 45,9 years with a standard deviation of $\pm 17,4$ years, being the higher prevalence of individuals between the ages of 51-60 years (27,1%), followed by the larger range of 60 years (22%), between 15-30 years (20,3%), 31-40 years (18,7%), 41-50 years (10,2%) and under 15 years (1,7%).

Regarding the civil State observed 28 (47,4%) cases between married, 25 (42,4%), 5 (8,5%), widowed and 1 (1,7%) divorced. In relation to schooling were the categories with the lowest educational level (illiterate, incomplete elementary school) with 35 (59,3%) of respondents and 24 (40,7%) in other categories of educational level (elementary school complete, incomplete high school, complete high school and higher education).

For categorization on the occupation, the participants were divided into two groups: economically active where 40 were registered (67,8%) of respondents and economically inactive (pensioners, unemployed and students home), who performed at number 19 (37,2%).

As the characterization of the subjects, operating 11 (18,6%) are classified as paucibacillary, 46 (78%) and 3 (3,4%) multibacillary presented other therapeutic schemes. Taking into consideration the clinical form 25 (42,2%) are in borderline (33,9%) 20 virchoviana, 7 (11,9%), 5 (8,5%) tuberculoid undetermined and 2 (3,3%) pure neural.

Only 17 patients had hansênica reaction, of which 13 (76,4%) of type I and 4 (23,6%) of type II. Only 11 showed ulcers, however two patients presented both prior as currently (at the time of collection) making a total of 9 (69,2%) current cases of ulcers and 4 (30,8%).

On the presence of associated diseases, 14 patients had a disease, and four respondents have submitted more than one concurrent disease. Among the disorders were hypertension 10 (55,6%) and diabetes mellitus by 6 (33,3%).

Analyzed the eight domains of the SF-36 questionnaire, you will find the summary table expressed in table 1. Five of the eight domains introduced minimum value equal to zero, and two had average below 50%, where the biggest score presented medium 59,79.

Table 1 - Average of the QOL domains of the SF-36 questionnaire. João Pessoa-PB, 2014

	Minimum	Maximum	Average	Standard Deviation (SD)
Functional Capacity	0	100	55,33	3 34,65
Physical Aspects	0	100	31,77	3 41,4
Pain	0	100	52,79	3 35,2
General State	5	100	59,79	3 27,22
Vitality	10	100	57,37	3 24,65

(To be continued...)

(Continuation)

	Minimum	Maximum	Average	Standard Deviation (SD)
Social Aspects	12,5	100	57,45	3 28,37
Emotional Aspects	0	100	35,58	3 45
Mental Health	0	100	57,89	3 24,56

Source: Own Elaboration. Joao Pessoa-PB, 2014.

To evaluate the factors that exert significant influence on quality of life (QOL) of patients affected by leprosy have been associated with the domains of QOL questionnaire SF 36 with the variables: sex, age, economic status, classification and operational presence of ulcers. In table 2 are described the variables and the QOL domains that have obtained value $p < 0,05$, showed statistically significant association.

Table 2 - Evaluation of the significance between the variables (sex, age, economic activity, ulcers and operational classification) and the domains of quality of life of the SF36. João Pessoa-PB, 2014.

	Sex	Age	Economic activity	The presence of ulcers	Operating rating
Functional capacity	p = 0,074 ¹	p = 0,017 ³	p = 0,084 ¹	p = 0,088 ¹	p = 0,943 ¹
Physical aspects	p = 0,940 ¹	p = 0,048 ³	p = 0,362 ¹	p = 0,510 ¹	p = 0,355 ¹
Pain	p = 0,575 ¹	p = 0,316 ³	p = 0,507 ¹	p = 0,563 ¹	p = 0,133 ¹
General health	p = 0,780 ²	p = 0,139 ³	p = 0,418 ²	p = 0,584 ²	p = 0,904 ²
Vitality	p = 0,142 ²	p = 0,761 ³	p = 0,823 ²	p = 0,377 ²	p = 0,211 ²
Social aspects	p = 0,329 ¹	p = 0,108 ³	p = 0,743 ¹	p = 0,546 ¹	p = 0,560 ¹
Emotional aspects	p = 0,140 ¹	p = 0,176 ³	p = 0,350 ¹	p = 0,218 ¹	p = 0,508 ¹
Mental health	p = 0,029 ²	p = 0,218 ³	p = 0,529 ²	p = 0,268 ²	p = 0,823 ²

Source: Own Elaboration. Joao Pessoa-PB, 2014.

¹ Test of Mann Whitney

² Test t student independente

³ Correlation of Pearson

As shown by Table 2, it can be observed that only two variables showed any Physical aspects Physical aspects association with regard to dimensions QOL. The sex presented value $p < 0,05$, for the domain Mental Health, while the age has remained associated with the functional capacity and physical aspects.

When evaluated more closely the data pointed to statistically as significant, we found the amount submitted by Tables 3 and 4.

Table 3 - association between the sex variable and domain QOL mental health.

Domains	Sex	N	Average (±DP)	p- value
Mental Health	F	27	50,37 3 27,80	P = 0,029 ²
	M	32	64,25 3 19,72	

Source: Own Elaboration. Joao Pessoa-PB, 2014.

² Test t student independent.

Table 4 - Association between the variable age and QV domains functional capacity and physical aspects

Domains	Correlation of Pearson	p- value
Functional capacity	r (Pearson) = -0,309	p = 0,017 ³
Physical aspects	r (Pearson) = -0,259	p = 0,048 ³

Source: Own Elaboration. Joao Pessoa-PB, 2014.

³ Correlation of Pearson

Depicting the QOL mental health domain, for which the variable gender showed statistically significant values ($p = 0,029$), can be observed (tab. 2) that the female obtained lower average score, which means a worse quality of life, the mental health aspect than the male.

Table 4 shows that the age is correlated negatively with the functional capacity and physical aspects (p -value $< 0,05$), i.e., as the age increases, the QOL scores tend to decrease.

DISCUSSION

The data obtained through this research reveal that most of the participants consists of people of the male sex (54,3%) with mean age of 45,9 years (standard deviation of $\pm 17,4$ years); married (42,4%) with low schooling (59,3%); economically active (67,8%) classified as multibacillary operationally (78%); are affected by leprosy borderline type (42,2%) showing the presence of current ulcers (18,6%) and hypertension (55,6%) and diabetes mellitus (33,3%) as diseases associated.

Corroborating with similar studies carried out in Manaus/AM in the period of 1998 to 2004¹² and in the city of Uberaba/MG for the period of 2000 to 2006⁵, is observed for this research the predominance of cases about the male population, the greater exposure of these disease, and less access to men's primary health services. In dissent, studies in Salvador/BA¹³, extreme southern Santa Catarina¹⁴ and in the northeast of Diamantina/MG¹⁵ emerge a superiority of females in relation to male, with regard to the involvement of leprosy, pointing out the women as protagonists in the demand for health services, and in the care with their self-image if compared to men, which makes the diagnosis.

Leprosy is known for its long incubation period, which favours the involvement of general adult population, i.e., in the economically active age group. That, consistent with

the results is similar to other studies, which highlight the economic losses that leprosy causes to the patient, family and society, due to its high crippling power that results in irreversible consequences if it is not diagnosed and treated early.^{16, 17, 5}

With regard to the civil State, prevailed the married/stable. In relating to education, studies in Brazil^{18, 19} converge with the results presented here, reinforcing the fact that Hansen's disease often affects people with low schooling, thus contributing negatively on individuals' understanding about the disease, its diagnosis and treatment.

As posted earlier, patients affected by Hansen's disease, commonly are in the economically active age group of the population. Once this has crippling features, becomes of great importance to completion of the assessment of the degree of disability of patients during treatment and after discharge in order to minimize the risk of loss in the ability to work and consequently on economic, social and psychological damage to the individual.^{17, 19, 20}

In research conducted in the northeast of Diamantina/MG¹⁵, was observed more people outside the labour market (46,5%) of which 33,3% needed clearance from their labour activities due to the complications generated by Hansen's disease.

Studies that evaluated the profile of patients with leprosy converge with findings of this survey showing a statistical superiority of Multibacillary cases in relation to a high quantitative as well as Paucibacillary patients classified with Borderline clinical form and Virchoviana^{21, 22}, which leads us to reflect on a possible late diagnosis of the disease.

Regarding the development of for leprosy reactions, some authors^{13, 23} reaffirm the data presented here, revealing a prevalence of type I reaction in research carried out in Salvador/BA in a specialized hospital¹³ may conclude the association between borderline clinical form and the triggering of the type I reaction. Furthermore, another risk factor for the development of this type of reaction is the treatment with multidrug therapy (MDT), which may occur during or after its completion.

The clinical characterizations of the subject, there have been cases with skin ulcers and diseases (HAS and DM). Skin ulcers are important complications related to the involvement of the nerves by the leprosy Bacillus, which causes neuropathy and, therefore, decrease the sensitivity of the peripheral members of the protective patients. In this picture, studies²⁴ involving self-care and early detection of cases of leprosy highlight the need of health education for prevention of these diseases. Regarding the presence of associated diseases is described in the literature²⁵, that the existence of a chronic condition already affects the quality of life of individuals.

Leprosy causes great harm to the daily lives and interpersonal relationships, causing suffering beyond the pain and malaise strictly linked to physical injury, with great social and psychological impact.

After the description of the subject, a comparison between the results obtained for the sample in the domains of the SF-36, in order to characterize the quality of life of the studied group. "The final score of the SF-36 can range from 0 to 100, where zero corresponds to the worse state of health, and 100, the best general health, being analyzed each dimension separately".⁹ On this relation, one can observe in the Tab 1, that the population studied presented better average for the domain QOL general condition, and worse for the QOL physical aspects.

The domains Physical and emotional aspect obtained score below 50, considered unsuitable for quality of life. It should be noted, however, that no size obtained medium scores close to 100, a fact that points how the sample has its general State of health and quality of life affected, although this is considered appropriate (score > 50).

In dissent, in Belém (PA) it was found that even though life has gone through major transformations after the diagnosis of the disease, living away from their families, isolated from society, because of the prejudice caused by sequelae; these patients are satisfied with their quality of life.²⁶

When tested association between the dimensions of the SF-36 and the variable gender, age, economic condition, operating classification of disease and the presence of ulcers, table 2, shows degree of significance only for sex and age. Referring the predominance of patients with Hansen's disease male, found in this study, we can infer that although these are more affected, deal better with problems related to anxiety, depression and emotional disarray than the female, a time that earned average scores better than this (Tab. 3).

Accordingly, a study evaluating the quality of life in patients with leprosy 10 exposed that men are less affected in their QOL than women, especially with regard to "functional capacity" and "Mental Health", suggesting the fact they deal better with the health/disease process.

As for age, the average presented among the participants was 45,9 years, being the most affected age group of 51 to 60 years (27,1%). The age and domains functional capacity and physical aspects were negatively correlated (Tab. 4), i.e., as age increases the QOL decreases. In this case, infers that the presence and extent of limitations imposed on physical capacity in leprosy worsens as the individual with leprosy becomes older.

Leprosy is a disease that affects mainly young adults.^{17, 23, 14} And for being a pathology that reperiuti negatively on psychological aspects, physical and social being highly disabling damage irreversible physical and functional capacity of individuals¹⁹, patients, causing great impact on QOL.

Evaluating the quality of life of patients during the treatment of leprosy, in Paraná, authors conclude that the physical domain is what most impacts on quality of life of these people.²⁷ In a study on the life story and work of people affected by leprosy, was appointed as a result of the change of life of subjects from the signs and symptoms of the disease,

varying in intensity and time for each. The bodily changes visible and invisible (nerve pain, areas under anesthesia, among others) led to the loss of part of QOL, reaching beyond the physical, the emotional people who feel confused in the face of so many changes.²⁸

With regard to age, older patients showed lower average quality of life in the physical aspect. This aspect is central to the quality of life of the elderly, who suffers with increasing age influences, as demonstrated in another study.²⁹

The assessment of the association between the economic condition, operating classification and the presence of ulcers, showed that none of the eight areas suffered significant variation ($p\text{-value} > 0,05$) in function of the SF-36. However it is important to highlight other studies which suggest that multibacillary patients present a greater impairment of quality of life compared to paucibacillary, once to represent the Group of individuals classified with the most severe clinical forms of the disease, have greater physical, psychological and social commitment.^{30,8}

Following controversial patterns the results presented, physiopathological gravity of leprosy justifies the presence of cutaneous ulcers resulting from serious physical disabilities compromising, so the functional capacity of individuals sick and consequently your QOL.^{7,31}

The process of illness associated with chronic diseases encourages the development of motor disabilities, psychological and social, limiting individuals and directly affecting their quality of life. When we refer to leprosy, this condition worsens, favoring social isolation, loss laborativas and therefore difficulty of acceptance of the process of illness and self-care, causing distress with repercussions on personal and professional life.³²

So, think of a humanized and common perspective refers directly to the need to improve the quality of life of these patients, either through the development of new research, interventions in health and/or public policies that make possible a priority and not negligence on leprosy.

CONCLUSION

As to the quality of life, through the questionnaire SF-36 concluded that the calculated average scores above values to 50 score feature, except for the physical and emotional aspects (score < 50), revealing that the general population has adequate quality of life, though, it is clear that it is affected by the disease.

The sample is mostly men, aged 51 and prevalent among 60 years of age, married, with low schooling, economically active, featuring the presence of multibacillary current ulcers and associated diseases.

Based on the results obtained, it can be affirmed that the physical and emotional aspects are of fundamental importance in the approach to the patient with leprosy, revealing that not only the State of disease, but several other factors deserve attention in the care to these customers.

The relationship between quality of life and chronic diseases in the health area has aroused the interest of researchers, so assess the QOL of patients affected by leprosy is also a priority for improving the welfare and practice of public health policies.

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